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GRANT NO: DAMD17-94-J-4334

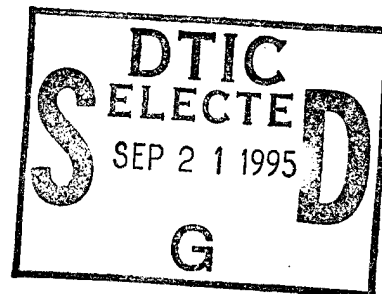
TITLE: An Evaluation of a Peer Support Program to Improve Quality of Life
with Breast Cancer

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REPORT DATE: July 28, 1995

TYPE OF REPORT: Annual Report



PREPARED FOR: U.S. Army Medical Research and Materiel
Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for public release;
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DTIC QUALITY INSPECTED 5

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REPORT DOCUMENTATION PAGE			Form Approved OMB No. 0704-0188	
Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503.				
1. AGENCY USE ONLY (Leave blank)	2. REPORT DATE July 28, 1995	3. REPORT TYPE AND DATES COVERED Annual 1 Jul 94 - 30 Jun 95		
4. TITLE AND SUBTITLE An Evaluation of a Peer Support Program to Improve Quality of Life with Breast Cancer		5. FUNDING NUMBERS DAMD17-94-J-4334		
6. AUTHOR(S) Dr. Carol P. Somkin				
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Kaiser Foundation Research Institute Oakland, California 94612-3433		8. PERFORMING ORGANIZATION REPORT NUMBER		
9. SPONSORING/MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012		10. SPONSORING/MONITORING AGENCY REPORT NUMBER		
11. SUPPLEMENTARY NOTES				
12a. DISTRIBUTION/AVAILABILITY STATEMENT Approved for public release, distribution unlimited		12b. DISTRIBUTION CODE		
13. ABSTRACT (Maximum 200 words) <p>The study will develop, implement and evaluate a volunteer peer support program for women with breast cancer which augments and complements the American Cancer Society's Reach to Recovery Program. Our aim is to determine whether it is worthwhile to provide a comprehensive, organizationally-specific, peer support program to women beginning at the time of diagnosis and continuing for up to one year.</p> <p>Participants will be paired with a trained breast cancer survivor, or "buddy," who will provide her, beginning at diagnosis, with ongoing peer support in addition to specific information and skills to help her navigate the Kaiser Permanente Medical Care Program. Volunteers will receive the standard Reach to Recovery training, in addition to a two-day training which will train them to become breast cancer advocates.</p> <p>The first year has been devoted to planning and laying the groundwork for implementation of the peer support program. Activities have included: (1) hiring project staff; (2) developing both the intervention and the volunteer training; (3) forging relationships with providers and staff in the study medical centers; (4) recruiting volunteers; (5) coordinating with the American Cancer Society staff; (6) developing subject recruitment procedures; and (7) developing the questionnaires.</p>				
14. SUBJECT TERMS Social Support, Patient Participation, Patient Satisfaction, Quality of Life, Evaluation			15. NUMBER OF PAGES 14	
			16. PRICE CODE	
17. SECURITY CLASSIFICATION OF REPORT Unclassified	18. SECURITY CLASSIFICATION OF THIS PAGE Unclassified	19. SECURITY CLASSIFICATION OF ABSTRACT Unclassified	20. LIMITATION OF ABSTRACT Unlimited	

FOREWORD

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 July 28, 1995

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Introduction

This report summarizes activities for the first year of a four-year study. The study will develop, implement and evaluate a volunteer peer support program for women with breast cancer which augments and complements the American Cancer Society's Reach to Recovery Program. Our major aim is to determine whether it is worthwhile to provide a comprehensive, organizationally-specific, peer support program to women beginning at the time of diagnosis and continuing for up to one year. We ask four research questions:

- (1) Does this expanded program improve (a) quality of life with breast cancer (b) participation in treatment decisions (c) satisfaction with care?
- (2) How do patient sociodemographic characteristics influence these outcomes?
- (3) What are the main benefits of this program?
- (4) Does participation in treatment decisions improve quality of life?

Participants will be paired (as closely as possible by age, marital status and ethnic background) with a trained breast cancer survivor, or "buddy," who will provide her, beginning at diagnosis, with ongoing peer support in addition to specific information and skills to help her navigate the Kaiser Permanente Medical Care Program. Volunteers will receive the standard Reach to Recovery training, in addition to a two-day training which will train them to become breast cancer advocates.

Body: Year 1 Activities

The first year has been devoted to planning and laying the groundwork for implementation of the peer support program. Activities have included: (1) hiring project staff; (2) developing both the intervention and the volunteer training; (3) forging relationships with providers and staff in the study medical centers; (4) recruiting volunteers; (5) coordinating with the American Cancer Society staff; (6) developing subject recruitment procedures; and (7) developing the questionnaires. Key staff will include the Project Coordinator who is responsible for the development of the training materials and volunteer trainings, the implementation of the trainings, and the collaboration with both the American Cancer Society and the various medical centers; and a Volunteer Coordinator who is responsible for the screening, selecting and supervising of the volunteers. The Volunteer Coordinator will also be responsible for the recruitment of subjects into the study and the matching volunteers and patients.

We conducted five focus groups with breast cancer survivors to ascertain their information needs, barriers to participation in treatment decisions and perceived ways to address these barriers. We held three multi-cultural focus groups, one group composed entirely of African American women and another group composed entirely of Latina women. The primary goal of these focus groups was to refine the plans for the intervention and volunteer training and ensure that the program would meet patient needs. (The moderator's guide for the focus groups is attached.) The focus groups were audiotaped, transcribed and analyzed for relevant themes.

Data from the focus groups support our initial concept of the intervention. Focus group participants provided strong validation for the dual importance of emotional support *and* information (beginning at diagnosis and continuing throughout the process of treatment and follow-up) to women with breast cancer. They also emphasized the unique value of peer support compared to other types of support from family, friends, and health care providers. Participants explained how emotional support--provided by another person who has "been there"--eases the fear which necessarily accompanies a diagnosis of breast cancer so that the newly diagnosed woman is able to take in the information needed to make decisions and begin to feel in control. Thus one participant elucidated how the provision of emotional support contributes to active participation in decision making: "My most important thing was the emotional support, because you can't make decisions when you are a physical wreck...And then I think once you're emotionally able to handle something, everything else seems to fall into place, because when you're calmer about it you can make decisions. (SRF51)" Another participant articulated the relationship between information and support: "I mean people need to be informed. And percentages and numbers always seem to, you know, do that factually. But for some people, they don't get numbers, and they don't feel percentages in the same way. That's why you really have to have somebody that can talk with you, and make you see the importance of something as obviously important as chemotherapy under certain circumstances... and you have to operate from knowledge and somebody has to be able to get you to understand. (HAY35)"

In the first year of the project we have met with providers and staff in the various medical centers to enlist their backing in referring appropriate women to be trained as peer support volunteers and in developing recruitment procedures for study subjects. We have also been meeting with health educators and nurses from each of the medical centers, who serve as consultants to the project, on ways to obtain provider support and buy-in. Similarly we have been meeting with representatives of the American Cancer Society to ensure their collaboration in the volunteer training. Volunteers trained by the project will have a dual identity as American Cancer Society Reach to Recovery volunteers and Kaiser Permanente Peer Support Project volunteers.

Volunteers will receive the standard Reach to Recovery training, in addition to a two-day skills training which will train them to become breast cancer advocates. (See attached training agenda.) As explained in the attached letter to Dr. Michael McCreery, recruitment and training of Peer Support Volunteers will be done incrementally. Recruitment of study subjects will be also phased in over several months. We have received input on the training from a number of sources including physicians, nurses, health educators, social workers, and a patient support organization, Women's Information Network Against Breast Cancer.

The objective of the training is to prepare carefully selected volunteers to provide ongoing emotional and informational support to breast cancer patients. The training will provide both information on the medical and psycho/sexual aspects of breast cancer and the skills needed to enable volunteers assist other women to access the resources of Kaiser Permanente and participate actively in treatment decision making. Volunteers will use role playing exercises to practice the various skills needed to be an informed consumer of medical care, including decision

making, communication, problemsolving and self care skills.

Conclusions

The first year has been spent developing the intervention and carefully laying the foundation for its implementation and evaluation. We will begin subject recruitment in September 1995.

APPENDIX

Breast Cancer Peer Support Project Focus Group Moderator's Guide

Introduction (5 Minutes)

Thanks very much for coming tonight. You have been invited tonight to help us plan a new program **INTRODUCE STAFF**. _____ will not actually be participating in the discussion; she will be assisting with any logistical problems that come up, listening to the discussion and taking a few notes. We will be tape recording the discussion so we can accurately capture all of your ideas without having to take detailed notes. This way I will be able to give my full attention to the discussion. All the information you provide will be kept confidential. No comments will be attributed to any specific individual.

Now I'd like to go over a few ground rules. The discussion tonight will last about two hours. We will be finished by 8 PM. We will not be taking a break, but feel free to get up and stretch or go to the rest room or get some more food. We are interested in hearing everyone's honest opinion. If your opinion is different from one that has already been shared, please tell us about it also. We are not looking to have everyone agree on a topic. We are looking for equal participation from everyone—all opinions are important so if some people are talking more than others, I may have to ask some of you to hold your comments until everyone has had a chance to speak. Please speak loudly and only one person at a time so that the tape recorder can pick up all of your ideas.

O.K. Lets begin our discussion.

I. (10 min) Participant Introductions

Tell us 3 things about yourself, including when you were diagnosed with breast cancer.

II. (40 min) Decision Making Question

Think about the process you went through in deciding what kind of treatment to have -- including all the different types of treatment, surgery, chemotherapy, hormonal therapy, radiation, and breast reconstruction.

- A. How did you go about getting and interpreting information about treatment options?
- B. Did you feel you had enough time, and were adequately prepared to make the right decision for you? (If yes why, if no why not?)
- C. How were the treatment decision decisions actually made?
- D. Who supported you during the time that you were making the decision?
- E. Did you feel satisfied with the decisions that you made and the process you went through to make the decisions?

- F. Knowing what you know now is there anything that you would do differently and what advice would you give to newly diagnosed woman?

III. (40 min) Peer Support Project Training

Describe program. Any questions?

- A. Think about the time when you were first diagnosed if you had been offered a buddy would you have taken advantage of this opportunity? Hand out sheet with volunteer roles. Circle the top three areas. Discuss reasons for choices.
- B. Imagine yourself as a peer support volunteer what kind of preparation and support would you need? Hand out sheet with possible training topics and ask to prioritize. Discuss choices.

IV. (20 min) Fear of Recurrence Q

It's normal to think about recurrence.

- A. How do you deal with it?
- B. What helps?
- C. What doesn't help?

V. (10 min) Positive Aspects of Breast Cancer

Crisis=danger and opportunity: Tell us one positive experience that has happened to you as a result of having breast cancer.

Peer Support Volunteer Role Description

Provide emotional support

Provide access to information that promotes patient understanding of available treatment options

Assist patient to clarify her personal beliefs and/or needs regarding treatment options

Assist patient to access the Kaiser Permanente Medical Care Program

Assist with self-care techniques and plans, e.g. nutrition, exercise, stress management

Anything else? _____

Peer Support Volunteer Training Agenda

Medical information about breast cancer

How to help women cope with the emotional aspects
of breast cancer

Communication skills

Decision making skills

How to access the Kaiser Permanente system

Problem solving skills

Self care skills

Anything else? _____

**American Cancer Society Reach To Recovery Training
Breast Cancer Peer Support Volunteer Project
August 4, 1995
Kaiser Permanente Medical Center-San Rafael
Conference Room D General Services Building**

8:45-9:00 Registration

9:00-10:00 Welcome and Introductions

10:00-11:15 ACS Reach to Recovery Program

Policy and Procedures

Karen Gebala, Field Services Manager, Marin County

Jane Kraft, Reach to Recovery Coordinator, Marin County

- Overview of Reach to Recovery Program
- The Reach to Recovery Visit
- ACS Programs: Look Good Feel Better, Special Touch, Transportation, Resources

11:15-11:30 Break and Stretch

11:30-12:30 What it means to be a Kaiser Volunteer

Prudence Kerr, Volunteer Director, San Rafael Medical Center

- Kaiser Permanente Volunteer Policies, Benefits and Procedures

12:30-1:30 Lunch

1:30-3:00 Medical Update: Panel Discussion

Ed Banks, MD, Chief of Surgery, San Rafael

Kathy Tucker, RN, Oncology Nurse

Anne De Laney, MD, Plastic Surgeon, San Rafael

- * Biology of breast cancer: types of breast cancer
- * Treatment Issues: types and side effects
- * Coping with treatment side effects
- * Reconstruction

Informal Break

3:30-4:00 Questions and Answers

4-4:30 Wrap-Up/Evaluation and Coming Attractions

Breast Cancer Peer Support Volunteer Project
August 5, 1995
Kaiser Permanente Medical Center San Rafael
Conference Room 4, Medical Office Building 2

- 8:45-9:00** **Registration**
- 9-9:30** **Welcome and Introductions**
- * Check-in
 - * Goals and Objectives of Training
 - * Personal Goals and Objectives (Volunteers)
- 9:30-11:00** **Psychological Issues**
- Value Clarification
 - Crisis/Loss/Change
 - Coping Styles and Skills
 - Dealing with Emotional Reactions
 - Reactions of Family and Friends
- 11:00-11:15** **Break**
- 11:15-12:15** **Body Image & Sexuality**
- Hormonal and psychological effects of breast cancer
- 12:15-1:15** **Lunch**
- 1:15-2:30** **Communication Skills**
- Listening Skills
 - When to listen, when to respond.
- 2:30** **Break and Stretch**
- 2:45-4:15** **Communicating with Your Health Care Team**
- Informing and taking PART
- 4:15** **Wrap-up and Coming Attractions**

Breast Cancer Peer Support Volunteer Project
August 11, 1995
Kaiser Permanente Medical Center
Conference Room 4, Medical Office Building 2

8:45-9:00 Registration

9-9:30 Check-in/Review Day

9:30-10:30 Problem Solving Skills

- ◊ Empowering your buddy
- ◊ Crisis Theory: in or out of balance
- ◊ Problem Solving Skills
- ◊ When and where to get help

10:30 Break and Stretch

10:45 Accessing and Navigating the Kaiser System

- Accessing the information and support needed
- Role of Volunteer

12:30-1:15 Lunch

1:15-2:30 Decision Making Skills

- Decision making during a crisis
- Role of the volunteer

2:30 Break

2:45-4:00 Self Care Skills
Caring for Yourself and for Your Buddy.

- ◆ Making healthy lifestyle choices: exercise, diet, relaxation
- ◆ Techniques and Resources

4:00-4:30 What is next? Wrap-Up/Evaluation

- Bi-monthly meetings
- Continued education: what other topics would you like to have covered?